Dystonia Support Group of Greater Washington DC

OCTOBER 2017

In Association with the Dystonia Medical Research Foundation

Dear Friends,

Our meetings are very informative and an opportunity to meet others dealing with dystonia of all forms. We are now planning our 2018 meetings etc, to be held in March , May and September 2018 and our all day symposium on November 4, 2018. Come and join our Core Group and share your ideas.

Our September 17, 2017 meeting featured speakers on two very important topics. Philip Goglas II, Legislative Aide with the Health and Medicine Counsel of Washington (which represents rare disorders on Capitol Hill) spoke on health care issues and the Affordable Care Act (ACA) implications for the dystonia community. Melanie Nupp, functional nutritionist spoke on "Maximizing physical functions of individualized nutrition approaches especially for persons with chronic conditions. To be the best we can be." If you were unable to attend Ms. Nupp's presentation and would like additional information about functional nutrition, you may contact her directly at (703) 946-3483 or melanienupp@gmail.com. Dr. Stephan Grill. MD, PhD, movement disorder specialist and medical advisor to our group, held a very informative Question and Answer session on topics raised by the attendees. Also in attendance were Dr, Zhen Xi MD and Shashi Ravindran MPH, MSN CRNP. Both are from the National Institutes of Health (NIH) in Rockville Md. They brought information about 12 dystonia clinical trials which need volunteers for them to help us. The trials' protocols are described in this newsletter. Please consider joining one or more of these trials so researchers may gain more knowledge about dystonia.

We are celebrating our 30 years as a dystonia support group. Our support group first started as the Baltimore-Washington Chapter 1987 by Christy Ludlou speech pathologist and Dr, Mark Hallett, director of HNCS at NINDS/NIH as medical advisor for the Baltimore - Washington Chapter of DMRF. The Washington chapter was headed by Richard Perlman and his wife. Mr. Perlman asked to step down in 1994 . I joined the group in October 1993. Meanwhile the DMRF decided to go to a volunteer run support model and divide the Baltimore and Washington Support Group. I was asked to lead the Greater Washington Support Group in May 1994. The Baltimore Group functions on line (social media). The Greater Washington Group does that also but we encourage face to face meetings at our four times a year meetings with speakers, Q and A sessions, newsletters, professional networks and telephone support. The Washington Support Group continued to meet at NIH until the 9/11 terrorist attack tightened security at NIH and a new meeting site had to be found. Holy Cross Hospital offered use of its Conference and Educational Center in 2001. This was a good development because the facilities are very modern and the hospital is located near a metro station as well as having adequate parking.

Join our celebration at our next support group meeting on November 19, 2017. Lunch will be provided gratis by John Gilligan (Medtronic, DBS fame developer), followed by a talk by Dick Stuart (leader of the NE Region NSDA and DMRF Support Group, long time friend and encouraging and inspiring speaker on "Life with Dystonia." Dr. Grill will give a talk on what we knew about dystonia when he came to NINDS/HCMS with Dr, Mark Hallett in 1990 compared to what we know now. We hope the Baltimore on line Support Group members will join us in this important meeting starting at 1 PM. It was a wonderful afternoon to gain a lot of new information and to meet with old and new friends.

Always,

Sally

Sally Presti, Support Group Leader of the
Dystonia Support Group of Greater Washington DC

Dystonia Support Group of Greater Washington DC
Support Group Meeting November 19, 2017

Location: Holy Cross Hospital, 1500 Forest Glen Road, Silver Spring, MD 20910-1484 (301) 754-7000

When: November 19, 2017 Informal social starts at 12:30PM, Program starts at 1:00PM

Agenda:

12:30 - 1:00	Social time to meet and greet friends
1:00 – 1:15	Sally Presti – Group announcements
1:15— 1:45	Lunch provided by Medtronic
1:45 – 2:30	Dr Stephen Grill, our group's medical advisor will discuss how treatments have changed over the last 30 years with a look to the future.
2:30 – 3:15	Dick Stuart, MC, DMin, psychotherapist —How to better navigate the dystonia journey.
3:15 – 3:30	Question and Answer

Speaker Dick Stuart, MC, DMin—Dick Stuart is a retired clergyman and psychotherapist. Mr. Stuart of New Hampshire is a DMRF Regional Coordinator and has led/participated in dystonia and spasmodic dysphonia (SD) support groups since the 1970s. Dick Stuart developed SD and writers' cramp while working as a pastor in Australia around 1974. His search for a diagnosis and treatment led through many doctor consultations, various muscle relaxant drugs, speech and voice therapy, psychotherapy and vocal rest for months. After 15 years he was correctly diagnosed (a life-changer!) and had many successful Botox injections over the next 25 years. In 2014 Dick was accepted by Dr. Gerald Berke at UCLA for the SLAD-R surgery. Recovery has been complete and freed Dick from the up-and-down aspect of Botox injection treatments. The connections he has made through the internet and his blog have widened awareness and encouragement for many others to consider SLAD-R surgery.

WE NEED TO HAVE AN APPROXIMATE NUMBER OF PEOPLE WHO WILL BE ATTENDING SO WE CAN ORDER LUNCH.
PLEASE RSVP TO
SALLY PRESTI AT (301) 627-1657 OR VIRGINIA FOSTER AT dcdystonia.editor@yahoo.com
We are planning gluten free and vegetarian options.
Please let us know if you have any other dietary restrictions.

NIH DYSTONIA CLINICAL TRAILS

The National Institutes of Health (NIH), National Institute of Neurological Disorders and Stroke (NINDS) is conducting the following clinical trails. NIH is asking individuals to participate in these trials in an effort to advance research. If you are interested in participating, please contact Ms. Shashi Ravindran at (301) 402-7129 or via email at shashi.ravindran@nih.gov Ms. Elaine Considine at (301) 435-8518 or considinee@ninds.hih.gov

Transcranial Magnetic Stimulation for Focal Hand Dystonia

Background: The brain has natural electrical rhythms of brain activities. These rhythms may be different in people with movement disorders, such as dystonia (involuntary muscle movement, cramps, or tremors). Understanding these rhythms may provide more information about movement disorders.

Focal hand dystonia, also known as "writer's cramp" or "musician's cramp," is a painful condition that affects the hand and arm muscles. Researchers want to use transcranial magnetic stimulation (TMS) to study brain rhythms in people with and without focal hand dystonia.

Objectives: To better understand brain rhythms involved in focal hand dystonia.

Eligibility: Individuals between 18 and 70 years of age who are right-handed and have focal hand dystonia. Healthy right-handed volunteers between 18 and 60 years of age.

Design: Participants will be screened with a physical exam and medical history.

This study includes two tests: a pilot test and a main test. The pilot test will determine the frequency of TMS that will be used in the main test. Participants may be in one or both tests. Each test requires a single outpatient visit that will last up to 5 hours.

Participants will have a base test to see how their muscles respond to TMS. This will look at the electrical activity of the muscles. Participants will have a wire coil held on their scalp. A brief electrical current will pass through the coil. It creates a magnetic pulse that stimulates the brain. Researchers will test the TMS on the right and left sides of the head. This will help find the spot that activates the finger muscles, and see how much TMS is needed.

In the main test, participants will have repetitive TMS (rTMS). rTMS involves repeated magnetic pulses delivered in short bursts. There will be four pulses in each burst. Participants will have multiple bursts during the test. This test will look at how the muscles of the hand and fingers respond to brain stimulation.

Treatment for focal hand dystonia will not be provided as part of this study.

Loss of Depotentiation in Focal Dystonia

Background: Focal dystonia is a brain disorder. It affects a muscle or muscles in a specific part of the body. Researchers think it may be related to excessive training or practice. They want to know more about how much training might trigger focal dystonia.

Objectives: To study why people develop focal dystonia. To study how brain plasticity changes with focal dystonia.

Eligibility: People ages 18 70 with focal dystonia. Healthy volunteers the same age are also needed.

Design: Participants will be screened with a physical exam and questions. They may have blood and urine tests. Participants will have up to 3 testing visits. Participants will have small electrodes stuck on the skin on the hands or arms. Muscle activity will be recorded. Participants will have transcranial magnetic stimulation (TMS). A wire coil will be placed onto the scalp. A brief electrical current will pass through the coil. The current will create a magnetic field that affects brain activity. Participants may be asked to tense certain muscles or do simple actions during TMS. A nerve at the wrist will get weak electrical stimulation. The stimulation may be paired with TMS for very short times. Participants will receive repeated magnetic pulses. Participants will receive a total of 150 pulses during a 10-second period. An entire testing visit will last 3 hours.

NIH DYSTONIA CLINICAL TRAILS (Continued)

Pathophysiology of Dystonia and Complex Regional Pain Syndrome

Background: Little is known about the problems in brain function in focal hand dystonia (FHD) or complex regional pain syndrome (CRPS) dystonia. It is unclear why some CRPS patients develop dystonia but others do not. Researchers want to learn which area of the brain is involved in CRPS dystonia compared with FHD.

Objectives: To understand why people with CRPS develop dystonia, and if these reasons are different in people with FHD.

Eligibility: Adults ages 18 - 70 with CRPS dystonia OR with CRPS without dystonia OR with FHD and Healthy volunteers of similar age.

Design: Participants will be screened with physical exam, neurological exam, and medical history. They may give a urine sample and will answer questions. Participants can have 4 - 5 outpatient visits or stay at the clinical center for approximately 5-6 days. Participants will have MRI scans. They will lie on a table that slides in and out of a scanner that takes pictures of their brain. They will do small tasks or be asked to imagine things during the scanning. Participants will have transcranial magnetic stimulation (TMS) sessions for a few hours, with breaks. A brief electrical current passing through a well insulated wire coil on the scalp creates a magnetic pulse. This affects brain activity. Participants may do small tasks during TMS. Participants will have the electrical activity of their muscles measured during TMS sessions. Small sticky pads will be attached to their hands and arms. Participants ability to feel 2 separate stimuli as different will be tested by using a weak electrical shock to their fingers. They will also be asked to feel small plastic domes with ridges, that may cause discomfort.

Propensity to Develop Plasticity in the Parieto- and Cerebello-Motor Networks in Dystonia From the Perspective of Abnormal High-Order Motor Processing

Background: People with dystonia have muscle contractions they can t control. These cause slow, repeated motions or abnormal postures. People with dystonia have abnormalities in certain parts of the brain. Researchers want to study the activity of two different brain areas in people with writer s cramp and cervical dystonia.

Objective: To compare brain activity in people with dystonia to that in healthy people.

Eligibility: Right-handed people ages of 18 60 with cervical dystonia or writer’s cramp. Healthy volunteers the same ages.

Design: Participants will be screened with a physical exam. They will answer questions about being right- or left-handed. At study visit 1, participants will Have a neurological exam, answer questions about how their disease impacts their daily activities, have a structural magnetic resonance imaging (MRI) scan. Participants will lie on a table that can slide in and out of a metal cylinder. This is surrounded by a strong magnetic field. Do simple computer tasks. At study visit 2: Participants will have transcranial magnetic stimulations (TMS) at two places on the head. Two wire coils will be held on the scalp. A brief electrical current creates a magnetic pulse that affects brain activity. Muscles of the face, arm, or leg might twitch. Participants may have to tense certain muscles or do simple tasks during TMS. They may be asked to rate any discomfort caused by TMS. Muscle activity in the right hand will be recorded by electrodes stuck to the skin of that hand.

NIH DYSTONIA CLINICAL TRAILS (Continued)

Cholinergic Receptor Imaging in Dystonia

Background: Dystonia is a movement disorder in which a person's muscles contract on their own. This causes different parts of the body to twist or turn. The cause of this movement is unknown. Researchers think it may have to do with a chemical called acetylcholine. They want to learn more about why acetylcholine in the brain doesn't work properly in people with dystonia.

Objective: To better understand how certain parts of the brain take up acetylcholine in people with dystonia.

Eligibility: Adults at least 18 years old who have DYT1 dystonia or cervical dystonia. Healthy adult volunteers.

Design: Participants will be screened with a medical history, physical exam, and pregnancy test.

Study visit 1: Participants will have a magnetic resonance imaging (MRI) scan of the brain. The MRI scanner is a metal cylinder in a strong magnetic field that takes pictures of the brain. Participants will lie on a table that slides in and out of the cylinder.

Study visit 2: Participants will have a positron emission tomography (PET) scan. The PET scanner is shaped like a doughnut. Participants will lie on a bed that slides in and out of the scanner. A small amount of a radio-active chemical that can be detected by the PET scanner will be given through an IV line to measure how the brain takes up acetylcholine.

Comparison of Electrophysiologic and Ultrasound Guidance for Onabotulinum Toxin A Injections in Focal Upper Extremity Dystonia and Spasticity

Background: It is hard for people with arm spasticity and focal hand dystonia to control their arm and hand muscles. They are often treated with botulinum toxin (BoNT) injections. Electromyography with electrical stimulation (e-stim) and ultrasound are used to find muscles for BoNT injection. Researchers want to learn which method is faster and more comfortable.

Objective: To compare 2 ways of finding muscles for BoNT injection for the treatment of focal hand dystonia and upper limb spasticity.

Eligibility: Adults 18 and older with focal hand dystonia or arm spasticity who have been getting onabotulinumtoxin-A injections in protocol 85-N-0195.

Design: Participants will be screened with medical history and physical exam. Participants will push or pull on a device that measures arm strength. They will have a neurologic exam. Women will have a pregnancy test. Participants will have a BoNT injection using either e-stim or ultrasound. For e-stim, sticky pads will be placed on the arm. A needle will be placed in the muscle. A small electric shock will be given through the needle. Then the injection will be given. For ultrasound, a probe will be moved across the skin. A screen will show an image of the muscles. Then the injection will be given. Participants will have a second injection 3 months later. They will have the method that was not used for their first injection. After each session, participants will rate their experience. Participants will have follow-up visits 1 month after each injection. They will be examined and asked about their response to treatment. Arm strength will be measured.

NIH DYSTONIA CLINICAL TRAILS (Continued)

Neurophysiologic Study of Patient With Essential Tremor and Dystonic Tremor

Background: Essential tremor is when a person has tremor, but no other neurological symptoms. Dystonic tremor is when a person also has dystonia. Dystonia is a condition in which muscle contraction causes changes in posture. Researchers do not fully know what areas of the brain cause these tremors, or how the types differ. They also do not know what tests can identify the differences.

Objective: To look at differences between essential tremor and dystonic tremor.

Eligibility: People ages 18 and older with or without tremor

Design: Participants will be screened with medical history, physical exam, and urine tests. Those with tremor will complete questionnaires about how tremor affects them. The screening and study visits can be done on the same day or on separate days. Participants will have 1 or 2 study visits. These include magnetic resonance imaging (MRI) and tremor testing. For MRI, participants will lie on a table that slides in and out of a cylinder that takes pictures. Sensors on the skin measure breathing, heart rate, and muscle activity. This takes about 2 hours. Tremor testing will include transcranial magnetic stimulation (TMS), electrical stimulation of the fingers, doing a movement task, and recording of tremor movements. For TMS, two wire coils will be held on the scalp and a brief magnetic field will be produced. A brief electrical current will pass through the coils. For the other tests, small sticky pad electrodes will be put on the skin. Participants will move their hand when they hear a sound. They will get weak electrical shocks to their fingers. These tests will take 3-4 hours. Participants can take part in either or both parts of the study.

Clinical and Physiological Studies of Tremor Syndromes

Background: Researchers have some data on how the brain controls movement and why some people have tremor. But the causes of tremor are not fully known. Researchers want to study people with tremor to learn about changes in the brain and possible causes of tremor.

Objective: To better understand how the brain controls movement, learn more about tremor, and train movement disorder specialists.

Eligibility: People ages 18 and older with a diagnosed tremor syndrome. Healthy volunteers ages 18 and older

Design: Participants will be screened with: Medical history; Physical exam; Urine tests; Clinical rating scales; Health questions; and they may have electromyography (EMG) or accelerometry. Sensors or electrodes taped to the skin measure movement. Participation lasts up to 1 year. Some participants will have a visit to examine their tremor more. They may have rating scales, EMG, and drawing and writing tests. Participants will be in 1 or more substudies. These will require up to 7 visits. Visits could include the following:

- EMG with accelerometry
- Small electrodes taped on the body give small electric shocks that stimulate nerves.
- MRI: Participants lie on a table that slides into a cylinder that takes pictures of the body while they do simple tasks.
- Small electrodes on the scalp record brain waves.
- A cone with detectors on the head measures brain activity while participants do tasks.
- A wire coil held on the scalp gives an electrical current that affects brain activity.
- Tests for thinking, memory, smell, hearing, or vision
- Electrodes on the head give a weak electrical current that affects brain activity.
- Photographs or videos of movement
- Participant data may be shared with other researchers.

NIH DYSTONIA CLINICAL TRAILS (Continued)

Deep Brain Stimulation Surgery for Movement Disorders

Background: Deep brain stimulation (DBS) is an approved surgery for certain movement disorders, like Parkinson's disease, that do not respond well to other treatments. DBS uses a battery-powered device called a neurostimulator (like a pacemaker) that is placed under the skin in the chest. It is used to stimulate the areas of the brain that affect movement. Stimulating these areas helps to block the nerve signals that cause abnormal movements. Researchers also want to record the brain function of people with movement disorders during the surgery.

Objectives: To study how DBS surgery affects Parkinson s disease, dystonia, and tremor. To obtain information on brain and nerve cell function during DBS surgery.

Eligibility: People at least 18 years of age who have movement disorders, like Parkinson's disease, essential tremor, and dystonia.

Design: Researchers will screen patients with physical and neurological exams to decide whether they can have the surgery. Patients will also have a medical history, blood tests, imaging studies, and other tests.
Before the surgery, participants will practice movement and memory tests.
During surgery, the stimulator will be placed to provide the right amount of stimulation for the brain. Patients will perform the movement and memory tests that they practiced earlier.
After surgery, participants will recover in the hospital. They will have a follow-up visit within 4 weeks to turn on and adjust the stimulator. The stimulator has to be programmed and adjusted over weeks to months to find the best settings. Participants will return for follow-up visits at 1, 2, and 3 months after surgery. Researchers will test their movement, memory, and general quality of life. Each visit will last about 2 hours.

The Dystonia Coalition Natural History and Biospecimen Repository for Isolated Dystonias (DCP)

Background: The purpose of this study is to create resources to help learn more about the isolated dystonias, myoclonus dystonia, and dopa-responsive dystonia and to develop and validate various dystonia rating scales.

Eligibility: Inclusion Criteria: Diagnosed with isolated dystonia or myoclonus dystonia or dopa-responsive dystonia. To be included in laryngeal dystonia group, nasolaryngoscopy (voice box exam) must have been completed to confirm diagnosis (this voice box exam is not part of the study)
Exclusion Criteria: Any evidence of a secondary cause for dystonia (other than myoclonus dystonia or dopa-responsive dystonia). Less than 2 months since last botulinum toxin injection. Inability to provide informed consent. Significant medical or neurological conditions that preclude completing the neurological exam Significant physical or other condition that would confound diagnosis or evaluation, other than dystonia or tremor.

Design: This collaborative, international effort has one primary goal. This is to create a biospecimen repository and associated clinical database to be used as a resource for dystonia and related disease research. Across sites, the investigators hope to enroll at least 5,000 adult patients. Subjects of this study will be asked to complete a neurological exam which will be video recorded, complete some questionnaires, and donate a blood sample. A study visit will take between 45 minutes and 1 hour. All subjects will be asked to return every 1, 2, 3, or 4 years for a one hour follow-up visit. People may participate in this study without agreeing to participate in the follow-up visits.

NIH DYSTONIA CLINICAL TRAILS (Continued)

Genetic Characterization of Movement Disorders and Dementias

Background: There are two basic types of movement disorders. Some cause excessive movement, some cause slowness or lack of movement. Some of these are caused by mutations in genes. On the other hand, dementia is a condition of declining mental abilities, especially memory. Dementia can occur at any age but becomes more frequent with age. Researchers want to study the genes of families with a history of movement disorders or dementia. They hope to find a genetic cause of these disorders. This can help them better understand and treat the diseases. This study will not be limited to a particular disorder, but will study all movement disorders or dementias in general. This study will perform genetic testing to identify the genetic causes of movement disorders and dementia. Today, genetic testing can be done to analyze multiple genes at the same time. This increases the chances of finding the genetic cause of movement disorders and dementias.

Objectives: To learn more about movement disorders and dementia, their causes, and treatments.

Eligibility: Adults and children with a movement disorder or dementia, and their family members. Healthy volunteers.

Design: Participants will be screened with medical history and blood tests. Some will have physical exam. Participants will give a blood sample by a needle in the arm. This can be done at the clinic, by their own doctor, or at home. Alternatively, a saliva sample may be provided if a blood sample cannot be obtained. Participants can opt to send an extra blood sample to a repository for future study. Genetic test will be done on these samples. The samples will be coded. The key to the code will remain at NIA. Only NIA investigators will have access to the code key. Participants can request to receive results of the tests. Participation is generally a single visit. Participants may be called back for extra visits.

Blepharospasm Tools

Background: Blepharospasm is a chronic disorder characterized by too many contractions in the muscles around the eye and nearby facial muscles, leading to involuntary eye closure. This study involves a comprehensive evaluation for patients with blepharospasm, other eye and face disorders, and people without any neurologic or eye or face disorders.

Eligibility: Diagnosed with Focal, Multifocal or Segmental Isolated Dystonia with Onset in Adulthood, must include blepharospasm.

Design: The study addresses abnormal movements of the muscles around the eye, pain in those muscles, psychological accompaniments, and impact on regular daily life. The evaluation for each participant will be done on a single visit, and it may take up to 1.5 hours to complete. Each participant in this study will be asked to do the following: Provide a copy of medical records and provide a medical history relating to the diagnosis of blepharospasm; Have an examination by a neurologist or ophthalmologist to reveal the features and extent of dystonia or other eye and face disorders; The examination will be video recorded so it can be reviewed later by different experts; Complete some questionnaires about quality of life and psychiatric well being. The doctors will also complete various scales and questionnaires based on the participant's study visit.

NIH DYSTONIA CLINICAL TRAILS (Continued)

Botulinum Toxin for the Treatment of Involuntary Movement Disorders

Background: The study examines the effectiveness of botulinum toxin as treatment for a variety of movement disorders. The goals of the study are to refine the technique of treatment to provide the best results, to improve the understanding of how botulinum toxin works on movement disorders, and find other conditions that may be treatable with botulinum toxin. In addition, researchers also plan to study the possible use of botulinum toxin F alone and in combination with botulinum toxin A in patients who do not respond to botulinum A toxin treatment.

Eligibility: Patients will be eligible for participation if they have a disorder that, in the judgment of the treating physician, might be amenable to treatment with BTX. Applicable disorders include but are not limited to dystonia, hemifacial spasm, blepharospasm, tremor, spasmodic dysphonia, tics, vocal fold tremor, oral lingual dyskinesia, tardive dyskinesia, spasticity, and spasmodic dysphonia.

Design: The efficacy of botulinum toxin (BTX) has now been demonstrated for a variety of diseases associated with involuntary muscle spasms or movement. The application of botulinum toxin therapy to movement disorders requires treatment tailored to the individual patient and specific techniques of injection. This protocol 1) provides for training of physicians in the use of botulinum toxin and 2) allows us to provide botulinum toxin injections for patients participating in other studies on the physiology of sensorimotor systems and physiological effects of botulinum toxin. Patients can be in the study at any one time either for the teaching value or for participation in other protocols, or both.

Diagnosis and History Study of Patients With Different Neurological Conditions

Background: The goal of this study is to diagnose and follow patients with disorders of movement control. Patients participating in this study will undergo routine laboratory tests and examinations in order to monitor their condition. Doctors at the NIH will work in cooperation with each patient's primary care physician. There will be no use of investigational treatments in this study.

Objective: This protocol is a screening protocol, which allows for evaluation of patients and families where neurological conditions are present for enrollment into other studies. It is also a teaching and training instrument for the MNB fellows, allowing them to gain expertise in the evaluation and treatment of patients. Finally, it will be used to screen healthy volunteers to create a pool of potential future HV matches for HMCS protocols.

Eligibility: Subjects with neurological disorders who are 2 years old or older, Family members who are 2 years old or older of people with a neurological disorder, Healthy volunteers who are 18 years old or older. National Institutes of Health (NIH) employees (other than those employed by HMCS in NINDS) may participate.

Design: The goal is to screen patients with neurological conditions and family members of patients with neurological conditions for enrollment in additional research protocols. No investigational treatments will be administered on this protocol and the NIH physicians will be playing a consultative role to the patient s primary physician. We will also screen healthy volunteers to create a pool of potential future HV matches for other HMCS protocols.

This is a natural history screening protocol to evaluate patients with neurological disorders and their family members, and to screen healthy volunteers for to create a pool of potential future HV matches other HMCS protocols. Therefore, there is no outcome measure.

Dystonia Support Group of Greater Washington DC Fund Raiser

If you wish to support our Dystonia Support Group of Greater Washington DC, please send your check to our treasurer, Hunter Webster at 1206 Night Star Court, Reston, VA 20194. Money is used to pay for publishing and posting our newsletter as well as supporting the DMRF. Dues paid are appreciated but not required.

Dystonia Support Group of Greater Washington DC New Member or Updates

If you wish to become a member of the Dystonia Support Group of Greater Washington DC or if you need to update how we contact you, please submit an email to Virginia Foster at dcdystonia.editor@yahoo.com or call Sally Presti at 301-627-1657.

STAY CONNECTED—BE A PART OF THE DMRF COMMUNITY

Stay in-the-know about our latest events and news

1. Renew your DMRF membership at https://www.dystonia-foundation.org/donate/donation_detail/472
2. Sign Up for Monthly Email Updates at https://visitor.r20.constantcontact.com/manage/optin/ea?v=001_tbYhe_1dqXPPVh0X0L8Fg%3D%3D
3. Text DYSTONIA to 90999 for Updates to Your Mobile
4. Find a Local Support Group at https://www.dystonia-foundation.org/living-with-dystonia/finding-support/finding-a-support-group
5. Join an online group at https://www.dystonia-foundation.org/online

For assistance with any of the above items, call DMRF at 800-377-3978

Dystonia Support Group Contact Information

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- **Hunter Webster**
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  hunter.webster@ihrco.com
- **Virginia Foster**
  Secretary/Membership/Newsletter
  301-904-3434
  Dcdystonia.editor@yahoo.com

Web Watch

- Our support group website is at http://www.dystoniadc.com/
- Dystonia related social forums are listed under the Web Watch page of our website at http://www.dystoniadc.com/
- The Dystonia Medical Research Foundation's website is https://www.dystonia-foundation.org/
- To search for clinical trials go to http://www.clinicaltrials.gov/ and www.centerwatch.com

Other Dystonia Support Groups

- DC Metro Spasmodic Dysphonia Support Group—contact Lois Jackson at loismjackson@hotmail.com
- Benign Essential Blepharospasm Research Foundation (BEBRF)—contact Barbara Benton at dir-e@blepharospasm.org or call
- 410-884-9048
- National Spasmodic Torticollis Association —Contact Margaret Teed at teed-fam@verizon.net or call 703-533-8698